

**Revised DRAFT**  
**LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM**  
**Task Force on Transitional Services & Supports**

**MEETING SUMMARY**  
**January 11, 2007**

The Task Force convened its first meeting on December 8, 2006 at the offices of the Alameda County Health Care Services Agency in San Leandro, California. The Chair of the Task Force, Mr. Dave Kears, and the Vice-Chair, Mr. Rick Rollens, welcomed the participants and summarized the opportunities and challenges before the Task Force. The Commission's Executive Director, Sue North, summarized the agenda for the day by asking the participants to focus first on identifying the most compelling policy problems associated with the range of issues facing persons with autism and ASD who are aging out of the school system and over the course of their adult lives.

After self introductions each participant raised their principal concerns and priorities. These issues were summarized and posted for participants to review. The group agreed to revisit the issues during the lunch break and "vote" thus indicating the issues which garnered the most widespread consensus for priority setting among the participants.

**Overview of the Issues**

The regional centers have experienced a massive increase in persons in with diagnosed autism over the last decade and these clients are going to be transitioning into adulthood over the next few years. Presently, the state's systems for adults with disabilities have not been designed to serve persons with autism. In addition, the needs of the estimated 75% of all persons with ASD who are NOT eligible for regional center services have not been assessed by any agency. These persons will likely also create new demands for public services in California including employment, adult education, supportive housing and self directed services beginning in the next three to five years. This "tsunami wave" needs to be recognized and policies need to be formulated to assure state programs adapt or are established to meet the needs of these populations.

If the state does nothing, these populations will likely repeat the tragic history of the seriously mentally ill after deinstitutionalization in California. Persons with ASD will be "served" by a public response one way or another—humane policies and informed programs or by poverty, homelessness and a dehumanizing criminal justice system.

The following summarize the major problems where consensus was reached during this meeting:

## **1. Lack of Interagency Collaboration and Coordination**

Persons with ASD transitioning into adulthood need a ‘life plan’—their educational, social, residential and employment needs need to be developed with the person, family, friends and community supporters. In the existing system, the range of persons with ASD are not eligible as a diagnostic group, while certain for many have no access to viable services; while others do have access in terms of eligibility but there are no services established or available:

- **EXAMPLE: Special education based students typically are not granted certificates or degrees thus exacerbating their access to the employment market; while other ASD students not in Special Education get no transition services whatsoever even though they have profound issues in transitioning into independent living**

Persons with ASD who qualify for regional center services will have lifelong assistance but face the prospect of access to services designed principally for other populations, while those persons with ASD not qualified for regional centers have no access to specialized programs even though they share some of the same disabilities. Thus far the state has reflected this population in state policy. Further, many state service programs for the disabled respond to crises when maintenance of functional level is often a critical goal. Services should not be predicated on a punitive model—offered only in response to a crisis.

State and local partnerships in policies and programs; public-private partnerships and programs; personalized planning based on the person’s strengths (“gift-based, not disability-based assessments and planning which assumes competence”)—all need to be done in the context of Interagency Collaboration and Cooperation. Further, the

## **2. Lack of Life Skills and Social Competency/Vocational Programs & Pathways**

There is a dearth of training and professional development, successful program models in vocational and adult education, and the full range of higher education systems (e.g., community college, state universities and the University of California) as it relates to persons with ASD. Those few programs that do exist in higher education for persons with disabilities focus largely on those with physical limitations. Persons with Aspergers’ Syndrome, as an example, frequently have high cognitive functioning but too often also have profound behavioral and socialization barriers that dramatically limit their ability to succeed in college. Yet they have great potential for making a significant contribution in terms of potential careers. The predominant model of vocational training is grounded in English only, lacks flexibility and is therefore not sustainable over a lifetime for too many people with this range of disabilities.

The scope of services needed for this population is very broad due to the eclectic nature of autism. There is a real need for developing models for how to test skills and talents,

how to assess strengths as well as weaknesses on an individualized basis. There is also a need for developing models for training and supportive employment for the same reason—this population represents a broad spectrum of people that, if served, could develop into a special talent pool for the state.

### **3. Lack of Services for Non-Regional Center ASD Population**

There is no designated public agency responsible for assisting ASD persons and their families with their specialized needs. The work world of today's California is described as one of constant transition throughout the course of an adult's life. Unlike the one employer for a career pattern of previous generations, experts predict that the average adult will likely have seven jobs through the course of their life. How will this reality affect the ASD population? Since some studies suggest that most ASD adults are unemployed, and as many as 85% of the families of children with ASD divorce, where will the adult caregivers of adult ASD persons find the help they need to secure independent living in the community for their loved ones as well as retraining and employment for themselves? As the adults with ASD age, where will they go to get help when they need it?

### **4. Public Awareness/ Community Acceptance of ASD Adults**

One item of total consensus was the need for better understanding by the public and agencies in the community about ASD. There are already reports of tragic incidents involving young teens when local police completely misconstrue ASD behavior results in real harm. We already know about the human costs of the state's criminalization of the mentally ill. We do NOT want the state to repeat any of those mistakes of public policy and neglect as seen in the mental health system over the past forty years! We need to initiate methods and policies to identify and divert ASD persons from the criminal justice system whenever possible. We need to assure the personnel in our criminal justice system have adequate training and skills to respond appropriately to ASD persons in the community.

### **5. Lack of Supportive Housing Plans and Programs**

Among the special needs populations of the state, persons with ASD represent a growing group emerging into adulthood which will need new options in supportive housing arrangements in our communities. Since it takes years to bring housing developments from planning to occupancy, the time to invest in this need is now. We know that over 30,000 persons with autism will be looking for living arrangements in the next few years. We need to expressly include design, planning and development for these supportive housing arrangements. Since ANY housing requires a significant investment to achieve even a modest increase in available housing, particular emphasis needs to be placed on

this need in order to assure future progress. There is a need for educating families and persons with ASD on housing options and to develop a continuum based on individual abilities and family circumstance. For those families with means, as an example, state policy ought to encourage family cooperatives to support the development of specialized housing.

## **6. Personal Safety and the Criminal Justice System**

The behavioral attributes of many persons with ASD make them vulnerable to misunderstandings in our criminal justice system. At the same time they are also personally vulnerable to those who would victimize. Not only are persons with ASD at risk for physical, emotional and sexual abuse, but special training and protocols need to be developed and conducted when allegations of abuse are made. The court system needs a degree of specialized training to assure justice is served for this population.

## **7. Medical Care Issues**

This population is unlike other generations before it in that so many more persons are being diagnosed today with ASD, especially in early childhood. As such, they are subjected to a wide range of medical treatment interventions, most of which have not been monitored before over a lifetime. Medical review, efficacy of early intervention techniques vs. other interventions in adolescence and adulthood, monitoring comorbid conditions along with adolescent development in a world that intervenes largely based on behavior---this population needs some special oversight in terms of the appropriateness, effectiveness and cumulative consequences of long term treatment and behavioral interventions.